

## *R-e-s-p-i-t-e Spells Respect*

We are just now beginning to hear – and understand – the voices of the millions of Canadians who care at home for aging, sick and disabled relatives. Most caregivers want nothing more than a little r-e-s-p-i-t-e.

It is clear that the fundamental reform of medicare will require substantial investment in the area in which most care actually is provided – at home. Home care has, indeed, been identified as a crucial but neglected building block in the ‘architecture’ of national health care. The need for this service will become increasingly pressing with our aging population.

The number of Canadians age 65 and over is expected to double from nearly 4 million in 2000 to almost 8 million by 2026. Although seniors are healthier and living longer than before, the fact remains that the incidence of disability rises with age. Statistics Canada reports that nearly half of older Canadians experience some form of functional limitation.

But even an investment in formal home care inadvertently may overlook the real anchor of the health system. Informal caregivers –

spouses, children, and close relatives and friends – provide 85 to 90 percent of care at home.

Take just one example of the scope of the problem. An estimated 364,000 Canadians age 65 and over have Alzheimer Disease or a related dementia. Fifty percent of these individuals live in the community. Of that group, 94 percent of their caregivers are unpaid family members, relatives or friends – 37 percent of whom are spouses and 29 percent of whom are daughters. And most of these caregivers are exhausted.

They live not only with the stress of physical caregiving. They live with the anguish of losing the soul of the person whom they love. They live with the fear of protecting a person who is prone to accident and injury. They live with the pressure of risking their career or even their job – if, indeed, they have to been able to maintain employment in the face of heavy caregiving responsibilities.

Despite the physical and mental exhaustion, not to mention cost, most caregivers would not have it any other way. They would not choose

anything other than to provide the support and attention that only they can – and want to – give.

Most caregivers just need a break. They need respite (sounds like ‘desperate’). How fitting.

In spite of its importance, respite is not well understood either by many of the organizations that deliver it or by governments that should be funding it. The term ‘respite’ often is used to refer to a uniform service in which an outside person – usually from a community organization – comes into the home for a designated period to allow caregivers some time off from their caregiving responsibilities.

This form of respite is necessary. In fact, it is essential. But it is not sufficient.

Caregivers gain relief, in reality, from many different types of assistance. They are the ones best able to identify what these are.

Several national studies have found that reprieve derives from a number of possible supports delivered within or outside the home. These supports include temporary breaks, a personal emergency system, information and training with respect to care receiver needs, adult day programs for the care receiver, housekeeping, outdoor home maintenance, counselling and peer support. Even being able to work a few hours or days a week is a relief for some caregivers who may worry about their financial circumstances or job security.

There are some exemplary projects under way throughout the country to test various models of respite. But these efforts are sporadic and seriously under-resourced in the absence of a national caregiver strategy.

The Manitoba, Saskatchewan and Atlantic Divisions of the Multiple Sclerosis Society of

Canada, for example, provided small cash payments directly to caregivers to meet their personal needs related to their caregiving role. The organization set no predetermined list of services, activities or items eligible for funding. Caregivers were encouraged to use these funds for their own individualized solutions.

In Montreal, a caregiver project operated by a group called The Lighthouse helped create physical and emotional respite for the parents of seriously ill children. A network of volunteers was trained to organize recreational activities adapted for the children’s specific needs.

The Alzheimer Society of Ottawa is working with several partners to develop a respite bungalow. The dwelling will be a temporary home for people with dementia. It will provide caregivers with breaks ranging from several hours during the day or night to three weeks of continuous care, up to a maximum 60 days per year.

If there is one conclusion to be drawn from the emerging models of respite, it is this: Caregivers experience relief in many different ways. Any program in respect of caregivers should allow them to choose from a range of options the most appropriate supports – whether for their own needs or those of the care receiver.

It is clear that respite is a word in search of understanding, support and respect. Others would argue that is precisely what it means.

A national caregiver strategy would be a significant step forward in meeting the needs of those unheralded Canadians who secure the foundation of our health care system.

*Sherri Torjman*

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1600 Scott Street, Suite 620  
Ottawa, Ontario, Canada K1Y 4N7  
phone: (613) 729-3340 fax: (613) 729-3896  
e-mail: [caledon@caledoninst.org](mailto:caledon@caledoninst.org)  
website: [www.caledoninst.org](http://www.caledoninst.org)